

Union Calendar No. 448

110TH CONGRESS
2D SESSION

H. R. 1553

[Report No. 110-706]

To amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to the current treatments and information regarding pediatric cancers, establish a population-based national childhood cancer database, and promote public awareness of pediatric cancers.

IN THE HOUSE OF REPRESENTATIVES

MARCH 15, 2007

Ms. PRYCE of Ohio (for herself, Mr. VAN HOLLEN, Mr. McCAUL of Texas, Mr. SESTAK, Mr. FERGUSON, Mr. CASTLE, Mr. YARMUTH, Mr. REICHERT, Mr. HASTINGS of Florida, Mr. SCHIFF, Mr. MICA, Mr. RUPPERSBERGER, Mrs. MUSGRAVE, Mr. LARSEN of Washington, Mr. GRAVES, Mr. PLATTS, Mr. CULBERSON, Mr. ENGEL, Mr. HIGGINS, Mr. BOUCHER, Mr. MORAN of Virginia, Mr. REYES, Mr. KILDEE, Mr. DREIER, Mr. CHANDLER, Mr. SESSIONS, Mr. GRIJALVA, Mr. SHUSTER, Mr. AL GREEN of Texas, and Mr. FORBES) introduced the following bill; which was referred to the Committee on Energy and Commerce

JUNE 10, 2008

Additional sponsors: Mr. GENE GREEN of Texas, Mr. ROGERS of Kentucky, Mr. CAPUANO, Mr. GERLACH, Mr. MOORE of Kansas, Mr. FORTENBERRY, Mr. DOYLE, Mr. TERRY, Mr. WEXLER, Mr. KENNEDY, Mrs. BOYDA of Kansas, Mr. HOLDEN, Mr. PICKERING, Mr. McCOTTER, Mr. MARSHALL, Mr. PATRICK J. MURPHY of Pennsylvania, Mr. WOLF, Mr. TOM DAVIS of Virginia, Mr. EDWARDS, Mr. ETHERIDGE, Ms. SUTTON, Ms. MATSUI, Mr. UPTON, Mrs. JO ANN DAVIS of Virginia, Mr. WAXMAN, Mr. MARKEY, Mr. ROTHMAN, Mr. WILSON of South Carolina, Mr. WICKER, Mr. MORAN of Kansas, Mr. MCGOVERN, Mr. DELAHUNT, Mr. DOOLITTLE, Mr. ALLEN, Mrs. DRAKE, Mr. PETERSON of Minnesota, Mr. HINOJOSA, Mr. GONZALEZ, Mr. BURTON of Indiana, Mr. CUELLAR, Mr. CANTOR, Mr. MEEHAN, Mr. WU, Mr. ALEXANDER, Mr. GORDON of Tennessee, Mr. LATHAM, Mr. CRAMER, Mr. WHITFIELD of Kentucky, Mr. ALTMIRE, Mr. LEWIS of Kentucky, Mr. OLIVER, Mr. WYNN, Mr. BOS-

WELL, Ms. BERKLEY, Mrs. MYRICK, Mr. PORTER, Mr. LANGEVIN, Mr. SIRES, Mr. RODRIGUEZ, Mr. SAXTON, Mr. ORTIZ, Mrs. JONES of Ohio, Mr. CUMMINGS, Mr. RUSH, Mr. NEAL of Massachusetts, Mr. BISHOP of Georgia, Ms. LORETTA SANCHEZ of California, Mr. HOLT, Mr. BRALEY of Iowa, Ms. EDDIE BERNICE JOHNSON of Texas, Mr. LYNCH, Mr. WAMP, Mr. McDERMOTT, Mr. TIBERI, Mr. PRICE of North Carolina, Mr. JINDAL, Mr. BARROW, Mr. DAVIS of Illinois, Mr. FATTAH, Mr. FRANK of Massachusetts, Mr. DAVIS of Kentucky, Ms. GRANGER, Ms. SOLIS, Mrs. MALONEY of New York, Mr. BRADY of Texas, Mr. RAHALL, Mr. ABERCROMBIE, Mr. WELCH of Vermont, Mr. KLEIN of Florida, Mr. SCOTT of Virginia, Mr. FILNER, Ms. ESHOO, Mr. GEORGE MILLER of California, Ms. HIRONO, Mr. HALL of Texas, Mrs. WILSON of New Mexico, Ms. KILPATRICK, Ms. MOORE of Wisconsin, Mrs. CAPPS, Mr. ISRAEL, Mr. FOSSELLA, Mr. KING of Iowa, Mr. LAMPSON, Mr. LOBIONDO, Mr. ELLISON, Ms. SCHAKOWSKY, Mr. LEWIS of Georgia, Mr. BARRETT of South Carolina, Mr. SHULER, Mr. KING of New York, Ms. ROS-LEHTINEN, Ms. ZOE LOFGREN of California, Mrs. LOWEY, Mr. BONNER, Mr. BERMAN, Ms. BALDWIN, Mr. PERLMUTTER, Ms. JACKSON-LEE of Texas, Mr. LANTOS, Mr. BLUMENAUER, Mr. CLAY, Mr. GALLEGLY, Mr. JOHNSON of Georgia, Mr. TURNER, Ms. DEGETTE, Mr. MURTHA, Mrs. MCCARTHY of New York, Mr. DOGGETT, Mr. COLE of Oklahoma, Mr. MATHESON, Mr. LUCAS, Mr. SPRATT, Mr. BACHUS, Ms. FALLIN, Mr. JEFFERSON, Ms. BORDALLO, Mr. COHEN, Mr. ROSKAM, Mr. CALVERT, Mr. COURTNEY, Mr. YOUNG of Alaska, Mr. DUNCAN, Mr. WELDON of Florida, Mr. HARE, Mr. HONDA, Mr. CLYBURN, Mr. MELANCON, Mr. WALZ of Minnesota, Mr. OBERSTAR, Mr. KAGEN, Mr. HINCHEY, Mr. DAVID DAVIS of Tennessee, Mr. LATOURETTE, Mr. ANDREWS, Mr. BARTLETT of Maryland, Mr. SERRANO, Mr. RAMSTAD, Ms. WOOLSEY, Mr. MITCHELL, Mr. RYAN of Ohio, Mr. BOOZMAN, Mr. GILCHREST, Mr. WESTMORELAND, Mr. ADERHOLT, Mr. JACKSON of Illinois, Mr. GINGREY, Ms. WASSERMAN SCHULTZ, Mrs. EMERSON, Mr. BUCHANAN, Mr. UDALL of Colorado, Mrs. CUBIN, Mrs. GILLIBRAND, Mr. PASTOR, Mr. NADLER, Mrs. BLACKBURN, Mr. FRELINGHUYSEN, Mr. INSLEE, Mr. BROWN of South Carolina, Ms. MCCOLLUM of Minnesota, Mrs. BIGGERT, Mr. EMANUEL, Mr. TIERNEY, Mr. WITTMAN of Virginia, Mr. MILLER of Florida, Mr. BOREN, Mr. LOEBSACK, Mr. CARNEY, Mr. WILSON of Ohio, Mr. TIM MURPHY of Pennsylvania, Ms. BEAN, Mr. SHERMAN, Mr. KIRK, Mr. PETRI, Mr. CARSON, Mr. MEEKS of New York, Ms. DELAURO, Mr. MURPHY of Connecticut, Mr. HELLER of Nevada, Mr. KUHL of New York, and Mr. SMITH of New Jersey

JUNE 10, 2008

Reported with amendments, committed to the Committee of the Whole House
on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italic]

[For text of introduced bill, see copy of bill as introduced on March 15, 2007]

A BILL

To amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to the current treatments and information regarding pediatric cancers, establish a population-based national childhood cancer database, and promote public awareness of pediatric cancers.

1 *Be it enacted by the Senate and House of Representa-*
 2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 *This Act may be cited as the “Caroline Pryce Walker*
 5 *Conquer Childhood Cancer Act of 2008”.*

6 **SEC. 2. FINDINGS.**

7 *Congress makes the following findings:*

8 *(1) Cancer kills more children than any other*
 9 *disease.*

10 *(2) Each year cancer kills more children between*
 11 *1 and 20 years of age than asthma, diabetes, cystic*
 12 *fibrosis, and AIDS, combined.*

13 *(3) Every year, over 12,500 young people are di-*
 14 *agnosed with cancer.*

1 (4) *Each year, about 2,300 children and teen-*
2 *agers die from cancer.*

3 (5) *One in every 330 Americans develops cancer*
4 *before age 20.*

5 (6) *Some forms of childhood cancer have proven*
6 *to be so resistant that even in spite of the great re-*
7 *search strides made, most of those children die. Up to*
8 *75 percent of the children with cancer can now be*
9 *cured.*

10 (7) *The causes of most childhood cancers are not*
11 *yet known.*

12 (8) *Childhood cancers are mostly those of the*
13 *white blood cells (leukemias), brain, bone, the lym-*
14 *phatic system, and tumors of the muscles, kidneys,*
15 *and nervous system. Each of these behaves differently,*
16 *but all are characterized by an uncontrolled prolifera-*
17 *tion of abnormal cells.*

18 (9) *Eighty percent of the children who are diag-*
19 *nosed with cancer have disease which has already*
20 *spread to distant sites in the body.*

21 (10) *Ninety percent of children with a form of*
22 *pediatric cancer are treated at one of the more than*
23 *200 Children's Oncology Group member institutions*
24 *throughout the United States.*

1 **SEC. 3. PURPOSES.**

2 *It is the purpose of this Act to authorize appropri-*
 3 *tions to—*

4 *(1) encourage the support for pediatric cancer*
 5 *research and other activities related to pediatric can-*
 6 *cer;*

7 *(2) establish a comprehensive national childhood*
 8 *cancer registry; and*

9 *(3) provide informational services to patients*
 10 *and families affected by childhood cancer.*

11 **SEC. 4. PEDIATRIC CANCER RESEARCH AND AWARENESS;**

12 **NATIONAL CHILDHOOD CANCER REGISTRY.**

13 *(a) PEDIATRIC CANCER RESEARCH AND AWARE-*
 14 *NESS.—Subpart 1 of part C of title IV of the Public Health*
 15 *Service Act (42 U.S.C. 285 et seq.) is amended by adding*
 16 *at the end the following:*

17 **“SEC. 417E. PEDIATRIC CANCER RESEARCH AND AWARE-**
 18 **NESS.**

19 **“(a) PEDIATRIC CANCER RESEARCH.—**

20 **“(1) PROGRAMS OF RESEARCH EXCELLENCE IN**
 21 **PEDIATRIC CANCER.—***The Secretary, in collaboration*
 22 *with the Director of NIH and other Federal agencies*
 23 *with interest in prevention and treatment of pediatric*
 24 *cancer, shall continue to enhance, expand, and inten-*
 25 *sify pediatric cancer research and other activities re-*
 26 *lated to pediatric cancer, including therapeutically*

1 *applicable research to generate effective treatments,*
 2 *pediatric preclinical testing, and pediatric clinical*
 3 *trials through National Cancer Institute-supported*
 4 *pediatric cancer clinical trial groups and their mem-*
 5 *ber institutions. In enhancing, expanding, and inten-*
 6 *sifying such research and other activities, the Sec-*
 7 *retary is encouraged to take into consideration the*
 8 *application of such research and other activities for*
 9 *minority, health disparity, and medically under-*
 10 *served communities. For purposes of this section, the*
 11 *term ‘pediatric cancer research’ means research on the*
 12 *causes, prevention, diagnosis, recognition, treatment,*
 13 *and long-term effects of pediatric cancer.*

14 “(2) *PEER REVIEW REQUIREMENTS.*—*All grants*
 15 *awarded under this subsection shall be awarded in ac-*
 16 *cordance with section 492.*

17 “(b) *PUBLIC AWARENESS OF PEDIATRIC CANCERS AND*
 18 *AVAILABLE TREATMENTS AND RESEARCH.*—

19 “(1) *IN GENERAL.*—*The Secretary may award*
 20 *grants to childhood cancer professional and direct*
 21 *service organizations for the expansion and wide-*
 22 *spread implementation of—*

23 “(A) *activities that provide available infor-*
 24 *mation on treatment protocols to ensure early*

1 *access to the best available therapies and clinical*
2 *trials for pediatric cancers;*

3 *“(B) activities that provide available infor-*
4 *mation on the late effects of pediatric cancer*
5 *treatment to ensure access to necessary long-term*
6 *medical and psychological care; and*

7 *“(C) direct resource services such as edu-*
8 *cational outreach for parents, peer-to-peer and*
9 *parent-to-parent support networks, information*
10 *on school re-entry and postsecondary education,*
11 *and resource directories or referral services for fi-*
12 *nancial assistance, psychological counseling, and*
13 *other support services.*

14 *In awarding grants under this paragraph, the Sec-*
15 *retary is encouraged to take into consideration the ex-*
16 *tent to which an entity would use such grant for pur-*
17 *poses of making activities and services described in*
18 *this paragraph available to minority, health dis-*
19 *parity, and medically underserved communities.*

20 *“(2) PERFORMANCE MEASUREMENT, TRANS-*
21 *PARENCY, AND ACCOUNTABILITY.—For each grant*
22 *awarded under this subsection, the Secretary shall de-*
23 *velop and implement metrics-based performance*
24 *measures to assess the effectiveness of activities funded*
25 *under such grant.*

1 “(3) *INFORMATIONAL REQUIREMENTS.*—Any in-
 2 formation made available pursuant to a grant award-
 3 ed under paragraph (1) shall be—

4 “(A) culturally and linguistically appro-
 5 priate as needed by patients and families af-
 6 fected by childhood cancer; and

7 “(B) approved by the Secretary.

8 “(c) *RULE OF CONSTRUCTION.*—Nothing in this sec-
 9 tion shall be construed as being inconsistent with the goals
 10 and purposes of the Minority Health and Health Dispari-
 11 ties Research and Education Act of 2000 (42 U.S.C. 202
 12 note).

13 “(d) *AUTHORIZATION OF APPROPRIATIONS.*—For pur-
 14 poses of carrying out this section and section 399E–1, there
 15 are authorized to be appropriated \$30,000,000 for each of
 16 fiscal years 2009 through 2013. Such authorization of ap-
 17 propriations is in addition to the authorization of appro-
 18 priations established in section 402A with respect to such
 19 purpose. Funds appropriated under this subsection shall re-
 20 main available until expended.”.

21 (b) *NATIONAL CHILDHOOD CANCER REGISTRY.*—Part
 22 M of title III of the Public Health Service Act (42 U.S.C.
 23 280e et seq.) is amended—

24 (1) by inserting after section 399E the following:

1 **“SEC. 399E–1. NATIONAL CHILDHOOD CANCER REGISTRY.**

2 “(a) *IN GENERAL.*—*The Secretary, acting through the*
 3 *Director of the Centers for Disease Control and Prevention,*
 4 *shall award a grant to enhance and expand infrastructure*
 5 *to track the epidemiology of pediatric cancer into a com-*
 6 *prehensive nationwide registry of actual occurrences of pe-*
 7 *diatric cancer. Such registry shall be updated to include*
 8 *an actual occurrence within weeks of the date of such occur-*
 9 *rence.*

10 “(b) *INFORMED CONSENT AND PRIVACY REQUIRE-*
 11 *MENTS AND COORDINATION WITH EXISTING PROGRAMS.*—
 12 *The registry established pursuant to subsection (a) shall be*
 13 *subject to section 552a of title 5, United States Code, the*
 14 *regulations promulgated under section 264(c) of the Health*
 15 *Insurance Portability and Accountability Act of 1996, ap-*
 16 *plicable Federal and State informed consent regulations,*
 17 *any other applicable Federal and State laws relating to the*
 18 *privacy of patient information, and section 399B(d)(4) of*
 19 *this Act.”; and*

20 (2) *in section 399F(a), by inserting “(other than*
 21 *section 399E–1)” after “this part”.*

Amend the title so as to read: “A bill to amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to information regarding pediatric cancers and current treatments for such cancers, es-

tablish a national childhood cancer registry, and promote public awareness of pediatric cancer.”.

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